General

Guideline Title

Care of the pediatric patient with a brain tumor.

Bibliographic Source(s)

American Association of Neuroscience Nurses (AANN). Care of the pediatric patient with a brain tumor. Chicago (IL): American Association of Neuroscience Nurses (AANN); 2014. 50 p. [244 references]

Guideline Status

This is the current release of the guideline.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Regulatory Alert

FDA Warning/Regulatory Alert

Note from the National Guideline Clearinghouse: This guideline references a drug(s) for which important revised regulatory and/or warning information has been released.

- December 14, 2016 – General anesthetic and sedation drugs : The U.S. Food and Drug Administration (FDA) is warning that repeated or lengthy use of general anesthetic and sedation drugs during surgeries or procedures in children younger than 3 years or in pregnant women during their third trimester may affect the development of children's brains. Consistent with animal studies, recent human studies suggest that a single, relatively short exposure to general anesthetic and sedation drugs in infants or toddlers is unlikely to have negative effects on behavior or learning. However, further research is needed to fully characterize how early life anesthetic exposure affects children's brain development.

Recommendations

Major Recommendations

The levels of recommendation (1-3) and the data quality classifications (I-IV) are defined at the end of the "Major Recommendations" field.

Epidemiology and Overview

Risk Factors

1. Nurses should be aware that children with hereditary syndromes may be at increased risk for brain tumors. Nurses caring for children with these genetic syndromes should observe for signs and symptoms that may suggest a central nervous system (CNS) tumor (Level 3).
2. Nurses should have a basic understanding of genetic predisposition as it relates to pediatric brain tumors. This knowledge should be used to assess a child's risk for developing CNS tumors (Level 3).
3. Nurses should possess awareness of the resources available to optimize care coordination and use a multidisciplinary approach to manage symptoms and improve function and quality of life (Level 2).
4. Nurses should know how to identify risk factors of hereditary syndromes that present unique and complex issues. Nurses will use this knowledge to guide families in future decision making and improve the care of long-term survivors (Level 2).
5. Nurses will assist families during genetic counseling by identifying personal risk and screening options, early detection methods, and risk-reduction strategies (Level 2).

Tumor Types

1. Nurses should apply their knowledge of tumor origins, functional anatomy, and physiology when completing a patient assessment (Level 3).
2. Nurses should correlate anatomical location of the brain tumor with clinical condition when monitoring for neurologic improvement or deterioration (Level 3).
3. Nurses should apply knowledge of tumor classification, site, tissue involved, and histology as they guide patients and families through the care continuum (Level 3).
4. Nurses should integrate basic comprehension of the molecular and histological diagnosis of pediatric brain tumors into patient and family education regarding treatment protocols specific to tumor subtype in preparation for treatment (Level 3).

Diagnostic Techniques

Computed Tomography (CT)

1. Nurses should advocate that CT scans only be performed when warranted to reduce exposure to radiation and decrease risk for radiation-induced cancer (Level 2).
2. Nurses should provide patient and family education regarding the signs and symptoms of acute renal failure if a patient receives a contrast CT in the outpatient setting (Level 2).
3. A licensed independent provider caring for the patient should be notified by the nurse if the patient demonstrates signs and symptoms of acute renal failure (Level 2).

Magnetic Resonance Imaging (MRI)

1. The patient should be assessed by the nurse prior to arrival into the MRI room to ensure that he or she is not wearing any metal and that there are no metal implants. This assessment will help to avoid potential harm or death (Level 3).
2. Nurses will ensure that a healthcare worker specially trained in MRI safety will perform an MRI screening assessment on the patient and any family member who will accompany the patient to the scanner prior to the exam and notify the ordering provider if the screening is positive for any metal devices (Level 2).
3. Nurses should educate patients regarding the large size of the MRI machine, the loud noise it makes, and the additional 10 to 15 minutes that some specialty MRIs necessitate. A child-life specialist should be consulted as needed to help provide age-appropriate education and distraction techniques (Level 2).
4. When the patient has a programmable ventriculoperitoneal (VP) shunt, the nurse will ensure that the setting has been verified, both prior to and after the MRI scan, and ensure that the shunt is reprogrammed after the MRI, if necessary (Level 3).
5. Before the imaging study begins, nurses should assess the patient for claustrophobia and their ability to lie still. The nurse should notify the provider if sedation or general anesthesia will be needed and administer sedation as prescribed (Level 2).
6. Serum blood urea nitrogen and creatinine levels should be drawn prior to a contrasted MRI as ordered by the licensed independent practitioner, and abnormalities should be reported to the ordering provider (Level 2).
7. Nurses should ensure that a functional large-bore peripheral intravenous (IV) catheter is in place when a patient will be receiving IV contrast (Level 2).
8. Nurses should verify nothing-by-mouth (NPO) status as appropriate for the specific test being performed and notify and educate patients and families (Level 2).
9. Nurses will inform the patient that the person performing the scan may ask them to perform certain movements or lie still (Level 3).

Biopsy

Nurses should have a basic understanding of the surgical technique for biopsy so they can prepare/educate the patient and family on what to

expect before and after surgery (Level 2).

Acute Care

Patient and Family Education and Support

1. Nurses must obtain an assessment to become familiar with a patient's baseline neurologic status, which allows the ability for comparisons to detect any acute changes (Level 3).
2. If the patient is an infant, the nurse should include the fontanel as a part of the neurologic assessment for signs of increased intracranial pressure (ICP) (Level 3).
3. Nurses should assess the family's and patient's level of understanding of the current diagnosis (Level 3).
4. Nurses should communicate openly and honestly using terms and methods appropriate to each family situation, taking into consideration education level, cultural background, and coping skills (Level 3).
5. Nurses should allow patients and family members to ask questions and provide answers as appropriate to the nurse's knowledge and role (Level 3).
6. Nurses should provide patients and families with writing materials so they may write down questions to prepare for their conversation with providers (Level 3).
7. Nurse should communicate next steps; for example, surgery, biopsy, pathology, and factors determining further treatment (Level 3).

Emergency Intervention

1. Nurses should monitor patients for signs and symptoms of increased ICP (Level 3).
2. Nurses should manage the external ventricular drain (EVD) to monitor ICP, maintain patency, and to drain cerebrospinal fluid (CSF) as prescribed (Level 3).

Medications Used During the Acute Phase

1. Nurses should use their knowledge of the potential side effects of steroid use in pediatric patients with brain tumors and provide ongoing assessment of possible symptoms, applying that knowledge to assess for complications associated with their use (Level 3).
2. Nurses should communicate any signs or symptoms that may indicate a need for steroid dose change with the healthcare team to assist in determining treatment duration and/or symptom management (Level 3).
3. Nurses should educate patients and/or family members regarding known side effects and their symptoms and assist them in symptom management (Level 3).
4. Nurses should teach patients and/or families that abrupt discontinuation of corticosteroids must be avoided, and that a taper schedule must be followed as prescribed (Level 2).

Seizures

1. Nurses should be aware of the potential risk and individual risk factors for seizures in pediatric patients with brain tumors and provide appropriate seizure care (Level 2).
2. Nurses should monitor for the side effects and drug interactions of antiepileptic drugs (AEDs) used in children with newly diagnosed brain tumors, particularly in patients receiving multiple classes of medications (Level 1).
3. Nurses should educate patients and families about compliance with AED therapy, drug interactions, and potential side effects (Level 1).

Surgery

Primary Goal

1. Because gross total resection of low-grade gliomas, if achieved with acceptable functional outcomes, offers the best chance for progression-free survival, nurses should emphasize preoperatively that technology (e.g., image guidance, functional brain mapping, intraoperative imaging, neurophysiological monitoring) has improved the safety of tumor resection, and gross total resection improves survival (Level 1).
2. When performing preoperative education with parents, nurses will use the knowledge that the most important prognosticator for outcome in children with most types of malignant brain tumors is the extent of the tumor removal. This education will provide important information when discussing preoperative preparation and surgical outcomes with the parents and patient (Level 3).
3. Nurses should know that brain stem gliomas can usually be identified noninvasively with the use of MRI and plan the patient's care accordingly (Level 3).
4. Nurses should be aware of the need for staged surgical resection because patients and families will need preparation and support if they are to undergo more than one surgical procedure (Level 3).

Shunts

1. During parent/patient education, nurses will mention in their discussion that fewer than 25% of children with malignant tumors require postoperative shunting based on information obtained in the late 1990s (Level 1).
2. Nurses will teach parents/patients that during the past 2 decades, the VP shunt has been used more cautiously for obstructive hydrocephalus. Instead, more radical tumor resections and more frequent use of endoscopic third ventriculostomy (ETV) are performed to reduce shunting (Level 2).
3. Nurses should be aware of signs and symptoms of hydrocephalus when assessing a child with a newly diagnosed brain tumor and closely monitor these children for early signs of neurological deterioration (Level 3).
4. Nurses should know that children with programmable valves must have their settings rechecked after MRI because the MRI magnet may alter the settings. Nurses will ensure that the need for shunt valve setting verification is communicated to all team members, and especially to the person responsible for performing the shunt reprogramming (Level 2).
5. Nurses will explain to parents that an Ommaya reservoir may be used to aspirate any recurrence of the cystic portion of the craniopharyngioma (Level 3).

Postoperative Complications

1. Nurses should reassure patients/parents that in regard to surgery for brain tumor resection, benefits generally outweigh risks. They should reinforce that surgery allows for diagnosis, symptom improvement, and reduction of tumor burden so other treatments such as radiation and chemotherapy are more effective (Level 3).
2. Nurses should carefully observe for signs of infection (fever, redness, discharge, swelling at incision site, stiff neck, photophobia) and hemorrhage (decreasing hemoglobin, increased heart rate, decreased blood pressure) and increased ICP (decrease in level of consciousness, bradycardia, hypertension) (Level 3).
3. Nurses should report CSF leaks to the patient's medical team immediately (Level 3).

Cerebellar Mutism Syndrome (CMS)

Careful follow-up for patients with CMS includes neuropsychological evaluation and critical support for patients and their families, and nurses should collaborate with the multidisciplinary team to provide these services (Level 3).

Electrolyte Disturbance

1. Nurses should collaborate and plan with neurosurgery, endocrine, and intensive care providers to monitor electrolytes after surgery in patients with brain tumor who undergo craniotomy, particularly patients who have suprasellar (i.e., germinoma, craniopharyngioma), thalamic, or hypothalamic tumors (Level 2).
2. Exogenous vasopressin/antidiuretic hormone, desmopressin acetate (DDAVP) may be ordered for patients with diabetes insipidus (DI), and fluid restriction may be required for patients with syndrome of inappropriate antidiuretic hormone (SIADH). Nurses will monitor intake and output, daily weights, and laboratory results such as urine and serum sodium and osmolality as ordered by the licensed healthcare provider (Level 3).
3. Nurses will administer DDAVP as ordered and monitor the outcomes of each treatment (Level 2).

Dysphagia Outcome

Nurses should be aware that children who undergo posterior fossa tumor resection are at risk for aspiration and should be considered for evaluation by speech pathology to detect any swallowing impairment before attempting oral feedings. Nurses should collaborate with the provider to obtain a swallow evaluation as needed (Level 3).

Lower Cranial Nerve Dysfunction

Nurses should know that children with intrinsic intramedullary tumors have lower cranial nerve dysfunction. With this knowledge, nurses should participate in discussions with parents about the possibility of postoperative tracheostomy and gastrostomy tube placement, but should also reassure them that most patients recover their lower cranial nerve function (Level 3).

Rehabilitation

1. Nurses should support and encourage appropriate rehabilitation referral services to improve function after brain tumor resection (Level 3).
2. Nurses should collaborate with the provider to obtain a speech-language hearing screen/evaluation as needed (Level 3).

Preparation for Surgery

1. Allowing parents to accompany their child into the operating room (OR) for induction of anesthesia in addition to premedicating the child with midazolam can decrease the parents' anxiety and increase their satisfaction (Level 1).
2. Nurses should advocate for parents to accompany their child into the OR and prepare the parent for what they may observe (Level 1).

Preoperative Shaving

1. When performing preoperative teaching, the nurse should explain that shaving the head is not necessary for wound healing and is done by physician preference (Level 3).
2. If the child is anxious about loss of hair due to preoperative shaving, the nurse should encourage the child and family to talk with the neurosurgeon about their concerns before surgery (Level 3).
3. The OR nurse may consider saving a small portion of a child's shaved hair to give to the parents, particularly if the child is an infant because this may be his or her first haircut (Level 3).

Pain

1. Nurses should carefully assess postoperative pain in patients who undergo craniotomy and consistently use age-appropriate pain scales (Level 3).
2. Nurses should recognize that older children or those who undergo lengthy procedures may need more medication to control their pain and administer analgesics accordingly (Level 3).

Venous Thromboembolism (VTE) Prevention

1. Nurses should assess risk factors of VTE in children with brain tumors, including immobility, prolonged bed rest, infection, obesity, and neurological surgery and take appropriate precautions (Level 3).
2. Nurses should implement prophylaxis such as early ambulation, adequate hydration, graduated compression stockings, and intermittent pneumatic compression devices (Level 3).
3. Nurses should discuss anticoagulant prophylaxis with the provider for children at high risk for VTE (Level 3).

Treatment

Risk-Adapted Treatment Strategy

Age Consideration

1. Nurses should recognize that children younger than 3 years of age with brain tumors have overall worse prognostic outcomes. Nurses should apply this knowledge to educate parents that intensive chemotherapy/biotherapy are often given to avoid or delay radiation therapy (RT) to the developing brain (Level 3).
2. Although certain malignant diagnoses (e.g., ependymoma) necessitate RT in the younger-than-3 age group, nurses should anticipate early signs of learning delay and assist parents in referral for neurocognitive evaluation, audiology, and neuro-ophthalmology follow-up (Level 3).

Types of Radiation

1. Nurses should be able to distinguish between the various methods of therapy that deliver radiation to the brain and the ways in which these methods may affect normal tissue surrounding the treatment area. They should use this knowledge to develop appropriate nursing care interventions (Level 3).
2. Nurses should teach patients/families to anticipate side effects dependent upon the type of radiation being administered (see Table 6 in the original guideline document) (Level 3).

Potential RT Complications

1. Nurses should articulate their role in providing continuity, alleviating anxiety, and managing potential side effects associated with RT (Level 3).
2. Nurses should advocate for child-life consultation during the simulation period, which will serve as a practice session for therapy as well as during RT (Level 3).
3. Nurses should provide daily continuity with interactive interventions and play therapy when child-life personnel are not available (Level 3).

Nursing Care

1. Patient and family education should include NPO instructions. Nurses should instruct the child and family that the child will not be able to eat or drink prior to sedation with RT (Level 3).

2. Nurses should maintain levels of competency in administering antiemetics, IV fluids, and blood products during the period surrounding RT to provide safe and effective care to their patients (Level 3).
3. Nurses should encourage the use of IV antiemetics for children receiving cranial and craniospinal radiation (Level 3).
4. Nurses should monitor for signs of low hemoglobin and hematocrit levels such as headache, fatigue, and pallor and administer packed red blood cells in patients per complete blood count results and as prescribed (Level 3).

Patient-Family Education Topics

1. Nurses should help parents to prepare their children for RT and anticipate potential stressors to reduce the child's overall distress (Level 3).
2. Nurses should help parents advocate for anesthetic creams for needle sticks/port access (Level 3).
3. Nurse should maintain communication with the child's oncologist regarding corticosteroid taper in relation to the fit of the immobilization mask (Level 3).

Chemotherapy

Types of Chemotherapy

1. Nurses should demonstrate competency in the administration and handling of all forms of chemotherapy to ensure the highest level of safe care (Level 3).
2. Nurses should follow safe-handling procedures and educate families to follow safe-handling procedures when administering or handling any form of chemotherapy or its waste products (Level 3).

Basic Classes of Chemotherapeutic Agents and Mechanisms of Actions

1. Nurses should have the knowledge to classify chemotherapy and biotherapy into basic categories as necessary to understand the mechanisms of action, side effect profiles, and supportive care interventions (Level 3).
2. Nurses should use this knowledge during administration of these medications to monitor for side effects during therapy (Level 3).

Patients are Often Eligible for Phase I/II Clinical Trials with Novel Agents When Other More Conventional Methods Have Failed

1. Nurses should recognize the goals of treatment, especially for patients who are relapsing/refractory, and use this knowledge to effectively communicate with patients and families, maintaining hope, but not offering false expectations. Nurses should reinforce that enrollment in a trial may or may not occur with intent to treat or cure disease (Level 3).
2. Nurses should be able to distinguish goals for treatment when interacting with the patient and family and communicate and formulate interventions appropriately (Level 3).

Nursing Care of the Child with a Brain Tumor

1. Nurses must be cognizant of the need to assess for both immediate and delayed chemotherapy-induced nausea and vomiting and assess this issue often and thoroughly (Level 2).
2. Nurses should appraise the need for antiemetics and familiarize themselves with the types of antiemetics needed in the anticipatory, acute, and delayed stages of chemotherapy-induced nausea and vomiting (Level 2).

Management of Chemotherapy Side Effects and Related Patient and Family Education

1. Nurses should incorporate family caregivers into anticipatory guidance for common adverse effects and recognize the vital role family caregivers play in the recognition and alleviation of symptomatic distress (Level 3).
2. Nurses should have knowledge and recognize the impact of a child's developmental stages on behavior and response to treatment (Level 3).
3. Nurses should instruct patients and families that fever and neutropenia are treated as a medical emergencies (Level 3).
4. Nurses should triage patients accordingly to obtain laboratory studies and blood cultures and administer antibiotics within 60 minutes of initial presentation with fever and neutropenia, as ordered by the licensed provider, to minimize potential complications associated with severe bacterial infection (Level 3).

Palliative Care and End of Life

<u>Entry into Palliative Care</u>

1. Nurses should expect introduction to palliative care in the setting of pediatric brain tumors to occur at diagnosis and facilitate this service with patients and families (Level 2).

2. A team approach should be coordinated by the nurse and accurate and reliable expectations should be conveyed by the healthcare team (Level 3).

Pain Control

1. Nurses should possess the knowledge to appropriately assess pain in children through the use of age-appropriate pain scales and awareness of nonverbal pain cues in dying children, such as wincing, grunting, and agitation (Level 3).
2. Nurses should advocate for patient use of age-appropriate pharmacologic and nonpharmacologic therapy to treat pain (Level 3).
3. Nurses should possess proficiency in the administration of analgesics via various routes (Level 3).

Seizures in Palliative Care Patients

Nurses should educate family members regarding the likelihood of seizures at end of life, first-aid management of seizures, and administration of different formulations of AEDs (Level 3).

Hospice Care

1. Nurses should evaluate parents' overall concerns related to their child's end-of-life trajectory and address those concerns when planning care (Level 3).
2. Nurses must educate parents about symptoms that may be observed during their child's end of life, especially signs of possible impending death (Level 3).

Nursing Care

1. Nurses should differentiate between curative and palliative chemotherapy when planning nursing care and interventions, especially as a child approaches end of life (Level 3).
2. Nurses should assess and appropriately manage both physical and psychological symptoms toward end of life to reduce both the patient's and family's suffering (Level 3).

Patient and Family Education

1. Nurses should recognize the importance of clear, effective communication with the patient and family throughout the disease process, especially nearing end of life, and work to provide clear and effective communication (Level 3).
2. Nurses should provide clear, accurate information; patients and families value honesty (Level 3).

Long-term Effects

Long-term Neurocognitive Effects

1. Nurses should educate patients and families regarding the potential for neurocognitive delay or regression (Level 2).
2. Nurses should work as active members of a multidisciplinary team to complete a comprehensive neurocognitive assessment evaluating cognitive functioning and academic achievement (Level 1).
3. Nurses should work with educators to encourage the provision of academic accommodations (e.g., allowing students more time to process information, one-on-one instruction, and reduced stimulation) (Level 2).
4. Nurses should make appropriate referrals to case managers or social services if a patient is not in a long-term program (Level 2).

Risk Factors for Neurocognitive Dysfunction

1. Nurses should be aware of the multiple risk factors for neurocognitive dysfunction and collaborate to provide multidisciplinary care (Level 2).
2. Nurses must have a thorough knowledge of a patient's chemotherapy and/or radiation regimen history as they educate patients and families and assist in interventions that will support symptom management of potential acute and long-term side effects (Level 2).
3. Nurses should proactively coordinate referrals to disciplines such as physical and occupational therapy for restorative and compensatory strategies to address muscle weakness and low physical performance (Level 2).

Interventions for Neurocognitive Dysfunction

1. Nurses should collaborate with the multidisciplinary team to inform parents and teachers about the cognitive sequelae associated with CNS cancer (Level 1).
2. Nurses should work as part of the multidisciplinary team to promote cognitive-behavioral training appropriate for childhood cancer survivors

within the school systems as needed (Level 3).
3. Nurses should refer or coordinate childhood cancer survivors to long-term follow-up programs for early social and educational intervention (Level 1).
4. Nurses should encourage the use of early intervention by using home-based, computerized cognitive training programs (Level 1).

Long-term Medical Effects

1. Nurses should emphasize the necessity of long-term ongoing health assessment to patients and their families because childhood cancer survivors often have one or more long-term medical effects (Level 2).
2. Nurses should assist patients and families in organizing long-term follow-up care (Level 2).
3. Nurses should monitor for seizures, provide first responder care, and notify the provider if seizures occur (Level 2).
4. Nurses should provide patient/family education on seizure precautions, including how to keep a seizure diary, and, if appropriate, medication instruction (Level 3).
5. Nurses should assess risk for health problems and create interventions to enhance patients' health status (Level 3).
6. Nurses should coordinate the referral of patients at risk for hearing loss for audiometry testing at baseline, during treatment, and during follow-up visits (Level 2).
7. Nurses should recognize and aid in the diagnosis and management of headaches and counseling of patients/families on preventative measures (Level 3).
8. Nurses should coordinate referral to a headache clinic or long-term cancer survivor clinic for patients with headaches who are off of treatment (Level 3).

Secondary CNS Tumors

1. Nurses should monitor for signs and symptoms of secondary tumors (Level 2).
2. Nurses should educate patients and families on secondary tumors and stress the importance of long-term follow-up care (Level 2).

Cardiovascular Disease

1. Nurses should recognize and assess for signs and symptoms of cardiovascular disease in long-term survivors (Level 2).
2. Nurses should educate patients on diet modification and physical activity as appropriate (Level 1).

Endocrine Deficiencies

1. Nurses should monitor and evaluate for endocrine effects, especially in children treated with cranial radiation and those in whom the condition is diagnosed when they are younger than 16 years of age (Level 3).
2. Nurses should educate patients and families regarding compliance with hormone replacement therapy and improvement in their diet (Level 3).
3. Nurses should stress the importance of long-term follow-up because these disorders may not become evident until years after treatment (Level 2).
4. Nurses should coordinate referral of patients/families to their oncologist to discuss the risk of infertility and the potential for harvesting eggs and sperm before treatment begins (Level 2).

Posterior Fossa Syndrome

Nurses should have a heightened knowledge of long-term consequences for patients with posterior fossa syndrome and make appropriate referrals if a patient is symptomatic (Level 2).

Musculoskeletal Effects

1. Nurses should monitor body composition, bone density, and lipid levels periodically (Level 2).
2. Nurse should encourage appropriate dietary calcium and vitamin D intake, weight-bearing exercises, and avoidance or cessation of smoking (Level 3).

Long-term Physical Effects

Physical Performance

1. If muscle weakness and low physical performance are present, nurses should refer survivors of childhood brain tumors to appropriate disciplines such as physical and occupational therapy for restorative exercises and compensatory strategies (Level 1).

2. Nurses should educate pediatric brain tumor survivors and caregivers that aerobic and resistance-training interventions may be of benefit to survivors with cognitive and other neurologic deficits and encourage patients to actively participate in these activities (Level 2).

Sleep Disturbance

1. Upon initial assessment of pediatric brain tumor survivors, nurses should ask about sleep-wake disturbances, especially excessive daytime sleepiness (EDS) (Level 1).
2. Nurses should screen for potential sleep-wake problems, especially EDS, as part of the routine follow-up of cancer survivors (Level 1).
3. Nurses should provide sleep hygiene education as appropriate and include timing of medications to provide best effect (Level 3).
4. Nurses should coordinate referral of patients for evaluation to a sleep center as appropriate (Level 1).

Oral/Dental Effects

1. Nurses should recognize the effects of cancer therapy on oral and dental health and educate patients and families on the importance of good oral hygiene (Level 2).
2. Nurses should facilitate referral to dental services for both preventative and treatment services (Level 2).
3. Nurses should recognize that oral and dental health is a multidisciplinary responsibility and encourage the entire healthcare team to include it in their daily assessment and plan of care (Level 2).

Neurobehavioral Effects

1. Nurses should advocate for the survivors' educational needs within the school system and for the necessity of long-term follow-up (Level 2).
2. Nurses should coordinate referrals for continued assistance for academic needs, psychological assessment, and long-term follow-up (Level 2).
3. Nurses should assess for suicidal ideation as part of the patient's psychological assessment. Many childhood cancer survivors have one or more medical or psychological issues (Level 3).
4. Nurses should be aware that childhood brain tumor survivors experience decreases in social adjustment following treatment and should refer survivors for neuropsychological testing as appropriate (Level 1).
5. Nurses should educate patients and families regarding potential medication (such as methylphenidate) options for the treatment of social adjustment issues and coordinate referral to a licensed independent care provider for further evaluation as appropriate (Level 2).
6. Nurses should educate patients and families regarding the necessity of continued support after treatment and the need to include siblings and friends (Level 1).
7. Nurses should coordinate and encourage referrals to comprehensive pediatric brain tumor treatment programs as needed for emotional support and resources for educating family, friends, and teachers about their illness and treatment plan (Level 1).

Quality of Life

1. Nurses should play a role in improving the quality of life of cancer survivors by providing education on patient medication, sleep hygiene, exercise, and depression and by making referrals to long-term follow-up centers specializing in childhood survivors of cancer (Level 2).
2. Nurses should provide early assessment and interventions for physical therapy and psychosocial services, especially for female survivors (Level 2).
3. Nurses should be aware that most cancer survivors have at least one significant long-term health problem and assess the patient accordingly (Level 2).
4. Nurses should educate cancer survivors about reproductive information before cancer treatment begins (Level 3).
5. Nurses should coordinate and encourage referral of cancer survivors to "survivorship clinics" or long-term clinics specializing in survivors of cancer to improve their health status and quality of life (Level 3).
6. Nurses should be aware that late effects experienced by childhood cancer survivors involve physical, medical, social, emotional, behavioral, and neurocognitive functioning, and it is crucial that nurses perform a holistic baseline assessment and provide appropriate interventions (Level 3).

Resource Assessment

1. Nurses should recognize that caregivers of cancer survivors are working through complex issues each day, and assess both the patient and family for the presence and effect of these stressors and provide appropriate interventions (Level 3).
2. Ease all aspects of patient and family complex issues through coordination of care and appropriate referrals (Level 3).
3. Assess needs and refer caregivers to the appropriate resources because financial concerns may contribute to missed follow-up appointments (Level 2).

4. Nurses should have knowledge about community resources that will help long-term survivors obtain needed resources, but they should exercise caution to avoid providing false hope regarding the accessibility of these resources (Level 2).
5. Nurses should recognize that transitioning from pediatric facilities to adult care involves unique concerns related to patients with chronic problems, and they should prepare patients and families for this transition (Level 3).
6. Nurses should assess patient and family knowledge regarding health insurance and refer cancer survivors to the appropriate resources and provide appropriate recommendations and interventions (Level 3).
7. Nurses should perform a comprehensive assessment of cancer survivors to determine needs (cognitive, emotional, physical, and financial) and educate on compensatory strategies including assistive technology (Level 2).
8. Nurses should be actively involved in designing the digital technology used to improve a patient's quality of life (Level 3).
9. Nurses should coordinate and encourage referrals to transitional facilities to promote independent living, job placement, and coaching, which will enhance quality of life for CNS malignancy survivors (Level 2).
10. Nurses should coordinate and encourage referrals as appropriate to multidisciplinary healthcare professionals such as social workers and neuropsychologists (Level 2).

Follow-up Care

1. Follow-up care and periodic screening based on assessment, tumor location, and type of treatment are a necessity, and nurses should educate patients and families and make referrals to long-term cancer centers or clinics (Level 2).
2. Nurses should educate patients and families of the critical importance of follow-up (Level 2).
3. Nurses should collaborate within organizations to place an effective reminder system in place targeting specific populations of cancer survivors because brain tumor survivors are less likely to continue long-term follow-up care (Level 2).
4. Nurses should educate childhood cancer survivors and their families about the increased risk for secondary tumors and other health conditions for more than 5 years after treatment (Level 2).
5. Nurses should be aware that because of high risk for mortality, subsequent cancers, and other medical conditions, survivors of pediatric brain tumors will require specialized care and screening in a cancer center or a clinic specifically intended for long-term follow-up of pediatric patients with brain tumors, and that it is critical to encourage and coordinate referrals as necessary (Level 2).
6. Nurses should use appropriate interventions during each phase of care, adapting and changing them to effectively address the varying needs of patients (Level 2).

Definitions:

Data Quality Classification

Class I: Randomized controlled trials without significant limitations or meta-analysis

Class II: Randomized controlled trials without important limitations (e.g., methodologic flaws or inconsistent results) and observational studies (e.g., cohort or case-control)

Class III: Qualitative study, case study, or series

Class IV: Evidence from expert committee reports and/or expert opinion of the guideline panel; standards of care and clinical protocols that have been identified

Levels of Recommendation

Level 1: Recommendations are supported by Class I evidence

Level 2: Recommendations are supported by Class II evidence

Level 3: Recommendations are supported by Class III and IV evidence

Clinical Algorithm(s)

None provided

Scope

Disease/Condition(s)

Brain tumor

Guideline Category

Counseling

Diagnosis

Evaluation

Management

Rehabilitation

Risk Assessment

Treatment

Clinical Specialty

Neurological Surgery

Neurology

Nursing

Oncology

Pediatrics

Radiation Oncology

Radiology

Intended Users

Advanced Practice Nurses

Hospitals

Nurses

Guideline Objective(s)

- To offer evidence-based recommendations on nursing activities that have the potential to maximize outcomes for pediatric patients with brain tumors
- To provide an up-to-date and thorough review and assessment of the literature; nursing care recommendations based on the evidence in the literature; and, in the absence of published scientific evidence, recommendations based on expert opinion
- To establish current and consistent practices among nurses providing direct care to pediatric patients with brain tumors
- To encourage bedside nurses to commit to evidence-based care and the development of evidence-based publications

Target Population

Patients ages 0 to 19 years with brain tumors

Interventions and Practices Considered

Diagnosis/Evaluation/Risk Assessment

1. Awareness/understanding of genetic dispositions for brain tumors and assessment of risk
2. Knowledge of resources to optimize care and use of a multidisciplinary approach
3. Patient assessment based on tumor origins, functional anatomy, and physiology
4. Monitoring for neurologic improvement or deterioration
5. Patient and family education/guidance
    - Assisting families during genetic counseling
    - Application of knowledge of tumor classification, site, tissue involved, and histology to guide patients/families through the care continuum
    - Integrating basic comprehension of the molecular and histological diagnosis of pediatric brain tumors into patient/family education regarding treatment protocols
6. Diagnostic imaging
    - Avocation of computed tomography (CT) use only when warranted to reduce radiation exposure
    - Post-imaging assessment for sign and symptoms of acute renal failure (for contrast CT)
    - Pre-imaging screening assessment and preparations prior to magnetic resonance imaging (MRI)
    - Monitoring serum blood urea nitrogen and creatinine prior to contrast-enhanced MRI
7. Understanding of biopsy to prepare/educate the patient and family

Treatment/Management

1. Patient and family education, including provision of written materials
2. Providing patients and families with support/comfort/resources
3. Recognition and reporting of evidence of cerebral edema and increased intracranial pressure (ICP)
4. Steroid management
    - Education of patient and family on steroid treatment and side effects
    - Monitoring and reporting of signs or symptoms that may require dose change
5. Management of seizures
    - Awareness of potential risk and individual risk factors
    - Monitoring for the side effects and drug interactions of anti-epileptic drugs (AEDs)
    - Education of patients and families about compliance with AED therapy, drug interactions, and side effects
6. Surgery
    - Understanding of surgical procedures, technology and outcomes
    - Preoperative education and supports for families
    - Postoperative pain assessment and administration of analgesics
    - Venous thromboembolism prevention
    - Monitoring and management of postoperative complications of craniotomy
7. Radiation therapy (RT)
    - Knowledge of RT techniques, preparation for RT and management of adverse effects
    - Provision of daily continuity with interactive interventions and play therapy
    - Provision of patient information and education concerning RT
8. Chemotherapy
    - Knowledge of chemotherapeutic agents and safe handling procedures
    - Management of adverse effects and monitoring of laboratory analyses
    - Patient and family education (adhering to chemotherapy regimen)
    - Knowledge and recognize the impact of a child's developmental stages on behavior and response to treatment
9. Facilitation of palliative/end-of-life care if indicated
10. Facilitation of rehabilitation
11. Referral or coordination for childhood cancer survivors to long-term follow-up programs for early social and educational intervention
12. Collaboration and provision of multidisciplinary care for neurocognitive dysfunction
13. Long-term follow up monitoring and care, including signs and symptoms of secondary tumors

Major Outcomes Considered

- Sensitivity and specificity of diagnostic tests
- Effectiveness of treatments (surgery, radiation and chemotherapy) for symptom and disease management
- Survival time (progression-free and overall)
- Adverse effects of treatment
- Surgical and postoperative outcomes
- Quality of life

Methodology

Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Hand-searches of Published Literature (Secondary Sources)

Searches of Electronic Databases

Description of Methods Used to Collect/Select the Evidence

A comprehensive review of literature published prior to July 2013 was performed using the PubMed/Medline, CINAHL, Cochrane, Google Scholar, and OVID databases. Key words (and combinations of them) included ICU management, acute seizures, resection, biopsy, pediatric, brain tumor, neuro-oncology, surgery, radiation, chemotherapy, end of life, palliative care, event-free survival, craniospinal radiotherapy, central nervous system tumor, oncology, patient reported outcomes, cognitive training, childhood cancer, social, academic, neuropsychologic, off therapy, pediatric oncology nursing, attention problems, survivorship, late effects, nursing roles, and cancer. Preference was given to randomized clinical trials, especially those performed within the last 5 years; however, historically significant literature was referenced in the absence of more current and rigorous research.

Secondary references were discovered from primary references, but all efforts were made to retrieve secondary references and give appropriate credit to the original author and/or study.

Online references were used sparingly, and sources are included in the reference list.

Textbook references such as Adamson, Bagatell, Balis, and Blaney (2011); Blaney et al. (2011); and chemotherapy administration guidelines (Ettinger & Rale, 2011) from the American Pediatric Hematology Oncology Nursing Society and other publications appropriate to the topic were reviewed, used, and cited in the absence of evidence of clinical trials.

Inclusion Criteria

Inclusion criteria were developed for the literature review and included:

- Subjects: Brain tumor and child
- Subjects: Human
- Age Group: 0 to 18 years
- Language: English only
- Types of articles
    1. Clinical trials
    2. Systematic review
    3. Meta-analysis
    4. Review articles

Exclusion Criteria

Exclusion criteria were developed for the literature review and included:

- Language: Other than English
- Age Group: >18 years
- Subjects: Animal (one exception made, Hedley-Whyte, E. T., & Hsu, D. W. [2004]. Effect of dexamethasone one blood-brain barrier in the normal mouse. Annals of Neurology, 19[4], 373-377.)

Number of Source Documents

A total of 88 primary references were found that were felt to be suitable for inclusion. A total of 170 secondary references were found that were felt to be suitable for inclusion.

Methods Used to Assess the Quality and Strength of the Evidence

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Data Quality Classification

Class I: Randomized controlled trials without significant limitations or meta-analysis

Class II: Randomized controlled trials without important limitations (e.g., methodologic flaws or inconsistent results) and observational studies (e.g., cohort or case-control)

Class III: Qualitative study, case study, or series

Class IV: Evidence from expert committee reports and/or expert opinion of the guideline panel; standards of care and clinical protocols that have been identified

Methods Used to Analyze the Evidence

Review of Published Meta-Analyses

Systematic Review with Evidence Tables

Description of the Methods Used to Analyze the Evidence

Not stated

Methods Used to Formulate the Recommendations

Expert Consensus

Description of Methods Used to Formulate the Recommendations

The *Clinical Practice Guidelines* and recommendations for practice are established based upon the evaluation of the available evidence. Resources and recommendations must describe the best practices that can enable registered nurses (RNs) to provide optimal care for people with brain tumors.

For this clinical practice guideline, a patient population, intervention, comparison, outcome (PICO) question was posed: For a pediatric patient with a brain tumor, what constitutes best care? Then, an outline of the content was developed by the 7 subject matter experts/authors.

Rating Scheme for the Strength of the Recommendations

Levels of Recommendation

Level 1: Recommendations are supported by Class I evidence

Level 2: Recommendations are supported by Class II evidence

Level 3: Recommendations are supported by Class III and IV evidence

Cost Analysis

Magnetic resonance imaging (MRI) technology uses a very large magnet and is the most cost-effective diagnostic study for children when a high suspicion for brain tumor exists.

Method of Guideline Validation

Peer Review

Description of Method of Guideline Validation

The guideline underwent peer review by a panel of reviewers listed in the original guideline document.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The type of supporting evidence is identified and graded for each recommendation (see the "Major Recommendations" field).

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

The recommendations may assist nurses in making appropriate choices when caring for pediatric patients with brain tumor and for supporting their families.

Potential Harms

- Common corticosteroid side effects include gastrointestinal effects, immunosuppression, weight gain, insomnia, behavioral changes, skin fragility, and electrolyte/metabolic disturbances. See Table 5 in the original guideline document for more information.
- Potential acute effects of radiotherapy include skin erythema, hyperpigmentation, ulceration and desquamation, alopecia, hypothalamic dysfunction, pituitary dysfunction, headache, somnolence/fatigue, dry eyes, pericarditis, radiation pneumonitis, mucositis, esophagitis, nausea, vomiting, diarrhea, abdominal cramping, anorexia, and malnutrition. See Table 6 in the original guideline document for more information.
- Hair loss is a common side effect of chemotherapy. See Table 7 in the original guideline document for more information on side effects of chemotherapeutic agents.
- In a prospective trial in 2012, focal cranial radiation therapy (CRT) provided no significant decrease in either cognitive or motor functioning 4 years after treatment. The study reports, however, that the children were developmentally impaired, indicating that surgery and/or the effects of the tumor have more influence on neurocognitive dysfunction than formerly identified.
- Many studies report that childhood cancer survivors have one or more long-term medical effects after treatment (e.g., headache; hearing

impairment; hydrocephalus/shunt dependence; neurogenic bowel/bladder; neuropathy including numbness and tingling in the extremities, which has been reported when treatment includes platinum-based chemotherapy; reduced loss of vision/visual field deficits).

- Seizures can occur more than 5 years after treatment. An increased risk of seizures may occur with radiation therapy (RT) and in younger children.
- Valproic acid (Depakene, Depakote) may have antitumoral effects, but thrombocytopenia and platelet dysfunction may occur, increasing the chance of intratumoral bleeding. It is also highly teratogenic, making it a significantly undesirable choice for females who have started their menses.
- Phenytoin and/or fosphenytoin (Dilantin) is also commonly used, especially for acute, prolonged seizures; however, levels need to be monitored for efficacy if it continues to be used for maintenance dosing.
- Levetiracetam can cause behavior changes such as irritability, mood swings, and irrational behavior.
- Sensory/motor deficits can develop after surgery including focal extremity weakness, truncal/appendicular ataxia, sensory deficits, and cranial nerve deficits.
- Stroke is a risk factor after RT.
- Nephrologic effects can occur, particularly after administration of platinum-containing chemotherapy.
- The most common postoperative complications are cerebrospinal fluid (CSF) leak leading to postoperative meningitis, wound infections, hematomas, and neurological deficits.
- Justifiable concerns about the toxicity of radiation in young children may contribute to the higher mortality seen in infants with brain tumors than in older children.
- Childhood brain tumor survivors are at increased risk for late endocrine effects, especially children treated with cranial RT and younger than 3 years of age.
- An increased risk for developing a secondary central nervous system (CNS) tumor resulting from cranial and spinal radiation is related to the dose of RT and younger age at diagnosis.
- A secondary cancer can occur 10 or more years after initial radiation.
- Cardiac complications can occur years after receiving RT.
- Risk factors for sleep disturbance include radiation, extensive surgery, and chemotherapy.
- Septicemia, nutritional compromise, significant pain, and long-term morbidity are recognized oral complications of cancer therapy. Negative effects include mucositis; viral, bacterial, and fungal infections; xerostomia; and dental abnormalities including root stunting, microdontia, hypodontia, and overretention of primary teeth.
- Social adjustment, social performance, and social skills are decreased in childhood brain tumor survivors after treatment.

Contraindications

Contraindications

Dexamethasone should be avoided as a premedication or prechemotherapy antiemetic in patients with brain tumors because of the ability of dexamethasone to decrease the permeability of the blood-brain barrier (BBB), resulting in decreased efficacy of the chemotherapy.

Qualifying Statements

Qualifying Statements

- The authors, editors, and publisher of this document neither represent nor guarantee that the practices described herein will, if followed, ensure safe and effective patient care. The authors, editors, and publisher further assume no liability or responsibility in connection with any information or Recommendations contained in this document. These recommendations reflect the judgment from the American Association of Neuroscience Nurses (AANN) regarding the state of general knowledge and practice in our field as of the date of publication and are subject to change based on the availability of new scientific information.
- Adherence to these guidelines is voluntary, and the ultimate determination regarding guideline application must be made by practitioners in light of each patient's individual circumstances. This reference is an essential resource for nurses providing care to pediatric patients with brain tumors. It is not intended to replace formal learning, but rather to augment the clinician's knowledge base and provide a readily accessible reference tool.

Implementation of the Guideline

Description of Implementation Strategy

An implementation strategy was not provided.

Implementation Tools

Resources

Staff Training/Competency Material

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

End of Life Care

Getting Better

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

American Association of Neuroscience Nurses (AANN). Care of the pediatric patient with a brain tumor. Chicago (IL): American Association of Neuroscience Nurses (AANN); 2014. 50 p. [244 references]

Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

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Guideline Developer(s)

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Guideline Committee

Not stated

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Clinical Practice Guideline Series Disclosure

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Guideline Status

This is the current release of the guideline.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Guideline Availability

Electronic copies: Available from the American Association of Neuroscience Nurses (AANN) Web site .

Availability of Companion Documents

The following are available:

- Care of the pediatric patient with a brain tumor. CPG online exam. Available from the American Association of Neuroscience Nurses (AANN) Web site .
- Care of the pediatric patient with a brain tumor. CPG Web cast. Available from the AANN Web site .

Patient Resources

None available

NGC Status

This NGC summary was completed by ECRI Institute on May 21, 2015. The information was verified by the guideline developer on July 21, 2015. This summary was updated by ECRI Institute on February 15, 2017 following the U.S. Food and Drug Administration advisory on general anesthetic and sedation drugs.

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